



More Than Memory: Understanding Lewy Body Dementia

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Aging, MCI, and Dementia



“Normal” Aging

Mild changes in attention and
short-term memory
Minor word-finding difficulty

Mild Cognitive Impairment

More changes than expected
for aging, but still fully
independent day-to-day

Dementia

Changes significant enough
to impact daily function and
level of independence

Increasing cognitive change and impact on daily function

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The Dementia Umbrella



An umbrella term for many diseases that cause progressive cognitive change

Alzheimer's disease

Most common cause; memory loss is usually the earliest symptom

Lewy body dementia

DLB and Parkinson's disease dementia; second most common neurodegenerative dementia

Vascular dementia

Caused by strokes or reduced blood flow to the brain

Frontotemporal dementia

Changes in behavior, personality, or language come first

Mixed dementia

More than one disease process present at the same time

Less common causes

Includes Huntington's, Creutzfeldt-Jakob, and other conditions

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"One Year Rule"



Lewy body dementia

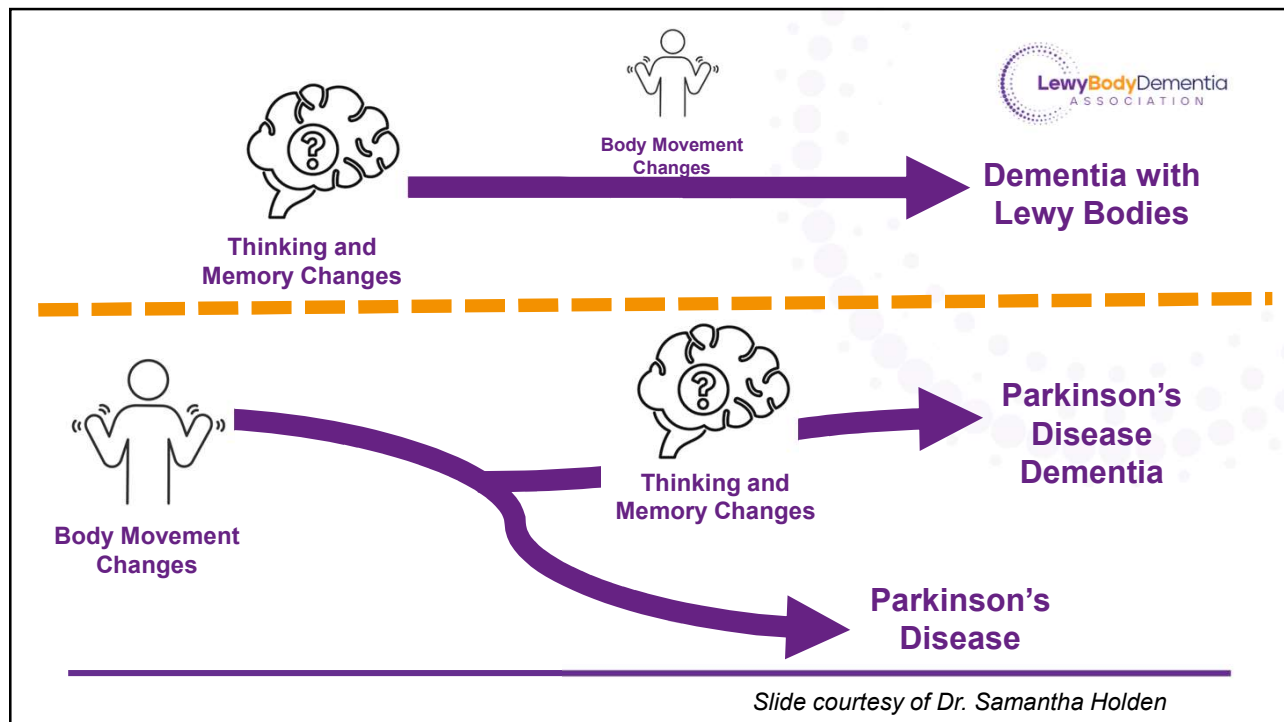
Parkinson disease
dementia (PDD)

*Development of dementia in the setting
of well-established Parkinson disease*

Dementia with
Lewy bodies (DLB)

*Development of dementia at same
time or prior to parkinsonism*

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What is a Lewy body?

A representation of a Lewy body...

The left side shows a microscopic image of a brain cell with a prominent, circular, eosinophilic inclusion body. An arrow points to it, and the caption below reads "Lewy body". The right side is a diagram showing the process of Lewy body formation. It starts with a wavy orange line labeled "Alpha-synuclein". An arrow points to a clumped, tangled mass of orange lines labeled "Misfolded & clumped". Another arrow points to a brain cell with a nucleus containing a circular orange inclusion body, labeled "Lewy body in a brain cell". The LewyBodyDementia ASSOCIATION logo is in the top right.

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Dementia with Lewy Bodies



**AMONG ALL
DEMENTIAS**
3-7%
of dementia
diagnoses in older
adults are DLB

TYPICAL ONSET
50+
age at which DLB
symptoms typically
begin

**PATH TO
DIAGNOSIS**
18 months
and 3 doctors, on
average, to reach
an accurate DLB
diagnosis

RANK
2nd
most common
neurodegenerative
dementia after
Alzheimer's

DLB is the most misdiagnosed dementia

DLB is the most expensive dementia

DLB is diagnosed when dementia appears before, or within a year of, the onset of parkinsonism — most diagnoses occur after age 65

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Parkinson's Disease Dementia



AT DIAGNOSIS
10-30%
newly diagnosed
with PD already
have cognitive
impairment

LIVING WITH PD
20-50%
have mild cognitive
impairment (MCI)

PROGRESSION
6-15%
of those with MCI
progress to
dementia each year

LONG TERM
~60%
will eventually
develop some
degree of dementia

4-6x higher risk of dementia than people the same age without PD

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How Does LBD Differ from AD?



Alzheimer's Disease (AD)

- Prominent memory problems
- Affects ability to store new information
- Gradual changes to memory and thinking
- Physical symptoms at later stages



Lewy Body Dementia (LBD)

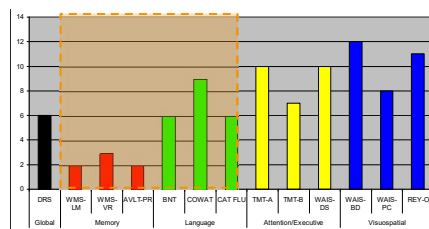
- Memory spared at the beginning
- Fluctuating abilities to think and remember
- Issues with problem-solving, attention, and reasoning
- Physical symptoms may be present at all stages
- Can include hallucinations and REM sleep behavior disorder

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Differences in Alzheimer's disease & Dementia with Lewy bodies



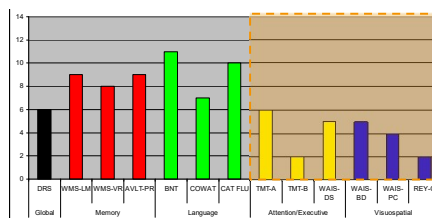
ADem



Greater impairments on:

- Memory measures
- Language measures

DLB



Greater impairments on:

- Attention/Executive measures
- Visuospatial measures

(Ferman et al, Neurology 1999)
(Ferman et al, Clin Neuropsych 2006)

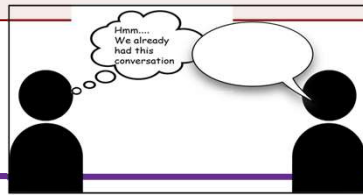
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Initial Cognitive Complaints



AD Dementia Memory

"Not retaining new information"
"Trouble recalling what was said or what happened recently"
"Repeats comments and questions"



DLB/PDD

Processing Speed and Attention

"Thinking is slower" • *"Lose train of thought easily"*
"Trouble keeping track of more than 1 thing at a time"

Visual Perceptual and Spatial Skills

"Trouble seeing, but eye doctor says there is nothing wrong"
"Trouble finding an item in a busy or cluttered area"



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Fluctuations in Attention and Alertness

Similar to Delirium:

Can vary within the hour, from hour to hour, or from day to day

Good



Poor

Alert, Awake

Coherent

Can concentrate, do multi-step tasks

Drowsy, Sleepy
"Zoned out"Less coherent, disorganized
Out of contextLose train of thought easily
Trouble with multi-step tasksLevel of
Consciousness

Speech

Attention/Abilities

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It's Not the Same...



EARLIER LOSS OF INDEPENDENCE

The **loss of independence** appears earlier than what is seen in Alzheimer's disease.

GREATER CARE DEMANDS

More rapid decline in function and increasing dependence may **increase resource use and cost of care in LBD** compared with AD.

Unique Challenges of LBD

- 1 Unique care partner burden
- 2 Earlier nursing home admissions
- 3 Higher costs
- 4 Misdiagnosed / under-recognized
- 5 Severe medication sensitivities

(Galvin et al., 2010; Huang et al., 2022; Joza et al., 2020; Kew et al., 2022; Zweig et al., 2014)

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Management of LBD



Treatments address the symptoms:

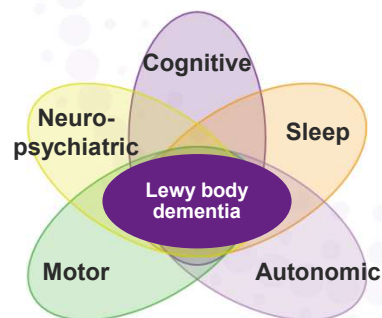
Cognitive/thinking impairments

Neuropsychiatric features

Motor features

Sleep disorders

Autonomic dysfunction



There is no cure and no disease-modifying treatments for LBD.

No medications are specifically indicated for dementia with Lewy bodies; medications are used off label to manage the constellation of symptoms.

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Medication Sensitivities in LBD



ANTIPSYCHOTICS

Many traditional antipsychotics (ex. haloperidol, thioridazine) block dopamine and can be dangerous.

SEVERE REACTIONS

Some can cause neuroleptic malignant syndrome (NMS) — fever, muscle rigidity, and breakdown that can lead to kidney failure.

BENZODIAZEPINES

Can actually increase anxiety and worsen cognition in people with LBD.

OVER-THE-COUNTER

Some OTC medications (ex. diphenhydramine) can also cause complications.



Up to 50% of people with LBD have a severe sensitivity reaction to antipsychotic medications — always review new prescriptions with the care team.

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Key Takeaways



1. LBD is an umbrella term

Dementia with Lewy bodies and Parkinson's disease dementia, distinguished by the one-year rule

2. It is more than memory

Fluctuating attention, visuospatial and executive changes, hallucinations and REM sleep behavior disorder

3. Often missed or misdiagnosed

It takes 18 months and 3 doctors on average to reach an accurate diagnosis

4. Independence is lost earlier

Function declines faster than in Alzheimer's, raising care partner burden and cost of care

5. No cure, no approved treatment

Medications are used off label, and antipsychotics can trigger dangerous sensitivity reactions

6. Education and support matter

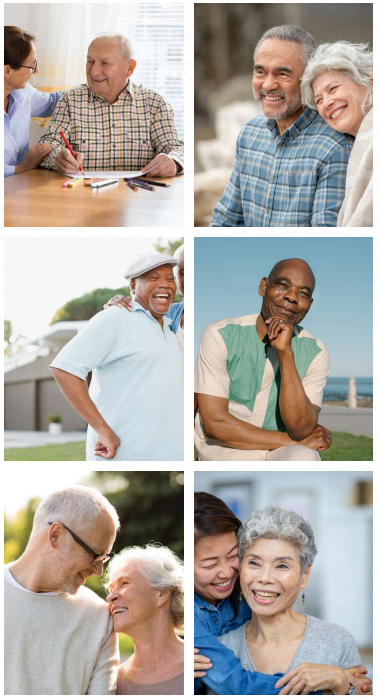
Early recognition, care partner support and trusted resources change the LBD journey

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Our Mission

To optimize the quality of life for those affected by Lewy body dementia, we accelerate awareness, advance research for early diagnosis and improved care, and provide comprehensive education and compassionate support.



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Thank You

Visit us at: lbda.org

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